

CREATING DEMENTIA- FRIENDLY COMMUNITIES

COMMUNITY TOOLKIT



UNDERSTAND ALZHEIMER'S
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The Alzheimer's Australia Dementia Friendly Toolkit was compiled utilising a range of international resources on dementia-friendly communities and age-friendly communities.

CREATING DEMENTIA-FRIENDLY COMMUNITIES A TOOLKIT: INTRODUCTION

What is dementia?

Dementia currently affects more than 332,000 Australians. There are many types of dementia but they are all diseases of the brain which invariably result in:

- Difficulties with memory
- Difficulties with everyday tasks, like handling money
- Difficulties with communication, such as language or word finding
- Difficulties with perception

Dementia is a progressive terminal disease with mild symptoms in the early stages of the disease which generally worsen over time. Dementia affects everyone differently, and in fact, not everyone you meet may have any visible symptoms.

What is a dementia-friendly community?

A dementia-friendly community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value. For people with younger onset dementia, this should mean the option of being supported to stay at work, like any other disabled person, as being dementia friendly is not only about social engagement. Each dementia-friendly community will look different, but may include:

- Businesses that provide accessible services to people with dementia including having staff who understand dementia and know how to communicate effectively with people who have dementia
- Employers that provide support for people living with the disabilities of dementia to continue with paid employment
- Volunteering opportunities for people with dementia
- Memory cafes for people with dementia and their families

- Choirs, walking groups, sporting clubs and social groups that are welcoming and inclusive of members with dementia
- Adult education facilities that provide opportunities to support new learning, for example courses at tertiary institutions, TAFE, or learning a new language or instrument.

Why do we need to be dementia friendly?

The growing numbers of people living with dementia will require a shift in how we respond to the needs of people living with dementia in the community. As the population ages, we will see an increase in the number of people living with dementia. By 2020, it is estimated that there will be around 400,000 with dementia and close to 900,000 people by 2050.

The majority of people with dementia live in the community. Often people feel socially isolated and wish that they had more opportunities to interact with people in the community and to participate in social or other activities. With the support of their employer, community, local businesses and organisations, neighbours, and friends and family members, people with dementia can continue to do many of the things they did before they received a diagnosis.

What do people with dementia say?

In 2014, Alzheimer's Australia conducted its first national survey of people with dementia identifying priorities for tackling the stigma and social isolation associated with dementia in the community. People with dementia indicated the need for changes to our communities to make them more dementia friendly and to support people with dementia to continue to live well and to be involved in the things they enjoyed before a diagnosis.

People with dementia identified the following priority areas in creating dementia-friendly communities:

1. Increasing community awareness and understanding about dementia
2. Improving access to social activities and opportunities for engagement including volunteering
3. Employment opportunities or support to remain employed
4. Access to appropriate health and care services to support them to continue to live at home for as long as possible
5. Access to affordable and convenient transportation options
6. Improved physical environments including appropriate signage, lighting and colours

Dementia-Friendly Toolkit

The Dementia-Friendly Toolkit aims to provide you with the information you will need to make your community or business more dementia friendly.

Information contained within the kit includes:

- Social and environmental checklists
- Guidelines for organisations to become dementia friendly
- Information for staff on how to effectively communicate with people with dementia
- Information on existing resources which could be used to increase staff awareness about dementia
- A guide to how to create a Dementia Alliance and developing an action plan to creating a dementia-friendly community
- A template letter to write to your local MP to support the development of dementia-friendly communities

Further tools and resources will be added to this toolkit in the coming months.

How can I be involved?

We would like to invite people with dementia, their family members, friends or carers, people from service clubs, shopkeepers, council workers to be part of the project...in fact anyone who is interested in making their community more dementia friendly can get involved! For more information, to see how you can be involved or to share your experiences please contact: dementiafriendly@alzheimers.org.au or phone 02 6278 8934.

WORKING TOWARDS



DEMENTIA FRIENDLY

THE DEMENTIA-FRIENDLY SYMBOL

Background

As part of Dementia Awareness Month 2014 Alzheimer's Australia will release a dementia-friendly symbol in addition to the guidelines in this kit for how organisations can become recognised as being dementia-friendly. The symbol was developed and endorsed by people living with dementia as a national symbol for raising awareness about cognitive impairment. The objective is for the abstract symbol to become recognisable across Australian communities to denote a business or community that is dementia friendly.

Initially in 2014 our goal is to target use of the symbol in a small number of organisations and communities where we are already doing pilot work (e.g. Kiama, Port Macquarie, Perth). This will enable us to test and refine the approach to use of the symbol and how it is monitored before a wider roll out.

The use of the dementia-friendly symbol

The symbol will initially be used in organisations working towards becoming dementia friendly. These organisations will make the commitment to be more aware of the needs of people with dementia and aim to provide an improved service. Displaying the dementia-friendly symbol will signify that the organisation has submitted an approved dementia-friendly action plan. The action plan will address the essential principles outlined in the Guidelines for dementia-friendly organisations.

The guidelines are available as part of the Dementia-friendly Business Toolkit available at www.dementiafriendly.org.au. For people living with dementia, seeing the symbol displayed, will mean that an organisation has staff who are specially trained and have an understanding of dementia.

In the longer term, the symbol will be used in a variety of ways, always with the involvement of people with dementia.

For more information about the dementia friendly symbol:

Please contact Alzheimer's Australia at dementiafriendly@alzheimers.org.au or Ph. 02 6278 8934

USEFUL RESOURCES FOR INCREASING AWARENESS ABOUT DEMENTIA

Is it Dementia Training Resource

The 'Is it Dementia' national training resource was produced by Alzheimer's Australia South Australia and was launched nationally in May 2013. The resource comprises a suite of 12 short films created by award winning filmmakers highlighting how dementia can impact the everyday work lives of Australians. The resource contains films, factsheets and facilitator guide questions for a range of industries including banking, transport, emergency services and retail. The resource aims to raise awareness of dementia and educate employees working in industries on the signs of dementia and considerations in effectively communicating with a person with dementia.

Further information about the resource can be obtained from: <http://isitdementia.com.au/>

Talk to Me Brochure

The Talk to me brochure was developed by the Alzheimer's Australia Dementia Advisory Committee to set out good communication tips for talking to people with dementia.

The committee hopes it will be used to help family, friends, carers, service providers, health professionals and the general community alike.

The Dementia Advisory Committee is made up entirely of people living with dementia. The committee's role is to advise and determine the priorities of people with dementia in regards to consumer advocacy, new policy, service delivery and program development. The committee is supported by Alzheimer's Australia.

A copy of the brochure can be obtained from: http://www.fightdementia.org.au/common/files/NAT/TalkToMe_Brochure_FoldedDL_HR.pdf

Dementia Enabling Environment Project (DEEP)

Alzheimer's Australia is working to address the gap between existing research about dementia-friendly environments and current design practices via a project which is funded through the Alzheimer's Australia National Quality Dementia Care Initiative (NQDCI). This national project aims to translate research into practice in the area of enable environments for people with dementia. The project website serves as a clearinghouse for information on:

- Resources
- Environmental audit tools
- E-newsletters
- Workshops for professionals and families
- A national library lending resource

Further information about the resource can be obtained from:

<http://www.enablingenvironments.com.au/>

Dementia Language Guide

Alzheimer's Australia has developed a 'Dementia Language Guide' alongside people living with dementia. The aim of the guide is to promote the consistent use of appropriate inclusive and non-stigmatising language when talking about dementia.

The words used to talk about dementia can have a significant impact on how people view or treat people with dementia in our community.

Respectful language is important and recognises that dementia is not the defining aspect of someone's life and does not prejudice their capacity or level of understanding.

Further information about the guide can be obtained from: www.dementiafriendly.org.au

Building Dementia and Age-Friendly Neighbourhoods Report

This paper identifies features that can help create optimum dementia and age-friendly outdoor environments. Those features have been compiled into the Alzheimer's Australia NSW Dementia-Friendly Outdoor Design Checklist, which is intended to help guide planners and policy makers when developing Community Strategic Plans, Development Control Plans (DCPs) and other planning instruments.

The paper also examines the literature, discusses the issues and makes recommendations for policy change to help ensure people with dementia and their carers can remain living in and connected to their neighbourhoods for as long as possible.

A copy of the report can be obtained from:

<http://www.fightdementia.org.au/common/files/NSW/20110803-NSW-PUB-DementiaFriendlyNeighbourhoods.pdf>

Dementia Training Study Centres (DTSC)

The DTSC aims to improve the quality of care and support provided to people living with dementia and their families through providing development opportunities for existing and future dementia care health professionals.

The DTSC provides a dedicated range of courses, workshops, seminars, scholarships, support, and curriculum development that translates contemporary knowledge into practical, effective approaches to helping people living with dementia and their families.

Further information about DTSC can be obtained at:

<http://www.dtsc.com.au/>

University of Tasmania- Understanding Dementia MOOC

The University of Tasmania's Massive Open Online Course (MOOC), Understanding Dementia, is a 9-week online course that builds upon the latest in international research on dementia. It's free and anyone can register. The curriculum draws upon the expertise of neuroscientists, clinicians and dementia care professionals in the Wicking Dementia Research and Education Centre.

Alzheimer's Australia Education and Training

Alzheimer's Australia offers a range of education and training services for people with dementia, family and friends of people with dementia, health professionals and care workers, community volunteers, members of the community and carer support group leaders.

To obtain further information regarding training and education available through your local Alzheimer's Australia office, please contact the Dementia Helpline on 1800 100 500.

DEMENTIA-FRIENDLY COMMUNITIES: STARTING A LOCAL DEMENTIA ALLIANCE

Do you want to make your local community more dementia friendly? You can start today by setting up a Local Dementia Alliance.

WHAT IS A LOCAL DEMENTIA ALLIANCE?

A Local Dementia Alliance is made up of people in the community you are interested in helping to make their community or town more dementia friendly. It must include people with dementia, alongside others such as carers and family members of people with dementia, local councils, business owners, community groups, schools and just about anyone who is interested. It must not be 'about people with dementia, without them'.

A Local Dementia Alliance will look different in every community depending on who is involved and the aims of the group.

FIVE STEPS TO GETTING STARTED

1. Find people who are interested in helping you

Gather together some interested people to help you. You could start with finding people with dementia, friends, family, neighbours and co-workers. Be sure to include people with dementia and their carers. Aim for 2-4 people who can help you set up a Local Dementia Alliance, but always include people with dementia.

With that group, think about the things you would like to try and achieve in making your community dementia friendly. Your list could include things like:

- Local businesses providing accessible services to people with dementia
- Knowing that staff understand dementia and know how to communicate effectively with people who have dementia.

- Employers supporting people with younger onset dementia to remain employed, in the same way people with other disabilities are.
- Improved signage in your town.
- Choirs, walking groups, sporting clubs and social groups that are welcoming and inclusive for people with dementia.
- Memory cafes for people with dementia and their families.

Once you have a general idea of what you may like to see you are ready to organise your first meeting!

2. Organise a meeting

Decide on a day, date and time to hold an information session about Dementia-Friendly Communities and setting up a Local Dementia Alliance.

Make a list of businesses and local community groups you think may be interested in taking part and talk to the owners about what it means to be dementia friendly. The information in the dementia-friendly businesses tip sheet can give you some ideas and help you do this.

Organise to speak to the relevant members of your local council about how they can become involved and invite them to attend the meeting.

Involving people living with dementia, their carers and families in a Local Dementia Alliance is central to ensuring your Alliance meets the needs of people in your community. Finding out from people with dementia, their carers and families about their experiences of living in the community; where they feel supported and where improvements can be made will help determine the work of the Alliance.

Spread the word. Encourage as many people as possible to attend a meeting to learn more about Dementia-Friendly Communities participate in a discussion. There are lots of ways you could promote the meeting

including, putting up posters on noticeboards in your local shopping centres and libraries; handing out leaflets; promoting it on social media; advertising in the community notices section, or sending a press release or letter to the local newspaper; having the meeting announced on the local radio station.

3. Make your first meeting a success

Introductions and welcome

Decide who is going to do the introductions and welcome everyone to the meeting.

Set the scene

Let everyone know why they are here and explain what you are trying to achieve. The concept of having Dementia-Friendly Communities is very new in Australia, so it is important to help people understand what it means and how they can help you achieve this goal.

Encourage people with dementia in the community to join the group, as well as speak to the group about what it means to them to live in a Dementia-Friendly Community so everyone has the chance to hear first hand what it means to different people.

Brainstorm

Facilitate a group discussion about different ways to make your local community more dementia friendly. Ask people to help identify dementia-friendly and unfriendly places around the town, including public buildings and spaces; the people who can answer those questions the most authentically and accurately are people living with dementia.

Recruit Alliance Members

Explain that a Local Dementia Alliance will work together on some of the issues identified during the brainstorming session. Ask for volunteers to join the Alliance and emphasise that everyone's contributions are valued and all are welcome. At the end of the discussion take note of who is interested in helping and how they want

to contribute. Do they want to be a member of on the Local Dementia Alliance? Can they offer support in another way? Make sure every is clear on their role and who is the main contact for the group. Depending on the number of people on the Alliance, it may be helpful to assign some roles such as Chair and Secretary to help run future meetings.

4. Take action!

Working successfully together as members of the Local Dementia Alliance will be a big part of helping your community become more dementia friendly. Working together with a focus on encouraging and supporting each other to be active members of the Alliance will be the key to your success.

Now that the group is set up it is time to take all your ideas a put them into a Community Action Plan. An action plan set out what you aim to achieve and helps you track your progress as you go.

Once you have your plan, make sure to follow up with members of the community, businesses, council members, local clubs and organisations who agreed to be involved to progress the actions you have agreed on.

It may be helpful to schedule regular meetings of the Local Dementia Alliance to help with achieve the goals in the plan.

5. Getting feedback

It will be important to get feedback from everyone involved as you progress the action plan to see how the actions of the groups are making a difference to people with dementia, their carers and families.

LOCAL DEMENTIA ALLIANCE

COMMUNITY ACTION PLAN TEMPLATE

| | | | |
|---|--|---------------------------------------|------------------|
| Who we are | List the members of your Local Dementia Alliance, including the businesses or community groups the represent (if applicable) | | |
| Our commitment to creating a dementia-friendly community | Briefly describe the main aims of the Alliance. | | |
| AIM | Outline the aim | | |
| Action | Responsibility | Timeline | Progress |
| List the possible actions that could be taken to achieve this aim | Who will be responsible | When will this action be completed by | Progress to date |
| 1. | | | |
| 2. | | | |
| 3. | | | |
| AIM 1 | | | |
| Action | Responsibility | Timeline | Progress |
| | | | |
| | | | |
| | | | |
| AIM 2 | | | |
| Action | Responsibility | Timeline | Progress |
| | | | |
| | | | |
| | | | |
| AIM 3 | | | |
| Action | Responsibility | Timeline | Progress |
| | | | |
| | | | |
| | | | |
| AIM 4 | | | |
| Action | Responsibility | Timeline | Progress |
| | | | |
| | | | |
| | | | |

| AIM 5 | | | |
|---------------|-----------------------|-----------------|-----------------|
| Action | Responsibility | Timeline | Progress |
| | | | |
| | | | |
| | | | |

| AIM 6 | | | |
|---------------|-----------------------|-----------------|-----------------|
| Action | Responsibility | Timeline | Progress |
| | | | |
| | | | |
| | | | |

Additional Information

This plan for the community of _____ was drafted on _____

Signed by members of the Local Dementia Alliance:

CREATING DEMENTIA-FRIENDLY COMMUNITIES CHECKLISTS

It is important to consider both the physical and social environment of a community in order to identify possible areas of improvement. There are a range of things you and your community can do to help people with dementia to remain engaged in the community in a meaningful way. This can be done by ensuring that the physical environment is easy to navigate and safe for people with dementia. Many of these suggestions are things that will benefit all members of the community. Some important things to consider when designing indoor and outdoor physical environments include:

| OUTDOOR AREAS AND BUILDINGS | |
|---|--|
| <input type="checkbox"/> Public areas and parklands are clean, well-kept and pleasant | <input type="checkbox"/> Adequate and evenly distributed street lighting to assist those with dementia and lower visual acuity |
| <input type="checkbox"/> Outdoor seating is safe, well maintained and adequate in number | <input type="checkbox"/> Level changes are clearly marked and well lit with handrails and non-slip, non-glare surfaces |
| <input type="checkbox"/> Undercover areas in parklands are provided to ensure accessibility in all weather conditions | <input type="checkbox"/> Buildings are well-signed outside and inside, with sufficient seating and toilets, accessible elevators, ramps, railings and stairs, and non-slip floors. |
| <input type="checkbox"/> Footpaths are wide, level where possible, non-slip, well maintained and free of obstructions | <input type="checkbox"/> Indoor and outdoor public toilets are well-maintained, clean, accessible and adequate in number with appropriate signage |
| <input type="checkbox"/> Bicycle pathways are separate from footpaths and other pedestrian walkways | <input type="checkbox"/> Bus shelters are enclosed and have adequate seating |
| <input type="checkbox"/> Adequate number of pedestrian crossings which are functional for people with different levels of disability with non-slip markings | <input type="checkbox"/> Street clutter including excessive signage, music, advertisements and bollards are minimal |
| <input type="checkbox"/> Pedestrian crossings have visual and audio cues and provide sufficient crossing time | <input type="checkbox"/> Background noise is minimal with acoustic barriers such as grass rather than hard surfaces, trees, hedges and fencing in place |
| <input type="checkbox"/> Visual landmarks are in place to assist way-finding such as garden beds, murals, water fountains/features, | <input type="checkbox"/> Signs have large graphics and symbols in clear colour contrast to the background, preferably dark lettering on a light background |
| <input type="checkbox"/> Building entrances are clearly visible and obvious | <input type="checkbox"/> Signs have non-glare lighting and non-reflective coverings |

| INDOOR AREAS | |
|---|--|
| <input type="checkbox"/> Steps clearly marked and lit, with guard and handrails on both sides, smooth, nonslip, non-glare surfaces, and nearby seating | <input type="checkbox"/> Sound absorbing materials, for example, acoustic ceiling tiles, wall hangings, upholstery and curtain fabrics used where possible |
| <input type="checkbox"/> Doors with lever-type handles and no more than 2 kilograms of pressure to open | <input type="checkbox"/> Indirect lighting for a good illumination level with reduced glare |
| <input type="checkbox"/> Uninterrupted visual access to all areas, ideally with unobstructed view of at least 6 to 30 metres in both directions in buildings and other indoor areas | <input type="checkbox"/> No areas of deep shadow or glaring light. |
| <input type="checkbox"/> Simple signage giving clear and essential information only | <input type="checkbox"/> Alarms/sirens/auditory cues on low frequency and at suitable pitch for people with low hearing acuity |
| <input type="checkbox"/> Signage fixed to walls at eye level (around 1400 - 1700m above floor level where possible) | <input type="checkbox"/> Corridors at least 2 metres wide to enable those less ambulant and wheelchair users to safely pass oncoming people |
| <input type="checkbox"/> Well-maintained, plain, smooth, level, non-slip, non-reflective floor coverings | <input type="checkbox"/> Where complete visual access is not possible, distinctive way-finding cues positioned at point where visual access ends. For example, potted plants, ornaments, paintings |
| <input type="checkbox"/> Flooring in clear colour contrast and material to walls and furnishings | <input type="checkbox"/> Furniture and furnishings should be contrasted against walls for easy visibility. Furniture should have rounded edges to reduce bumps and grazes |
| <input type="checkbox"/> Changes in texture or colour of floor coverings to indicate potential hazards | <input type="checkbox"/> Simple layout with non-uniform, short, direct routes |
| <input type="checkbox"/> Colour contrast toilet seats with toilet bowls and floor and uniform signage for male and female toilets | <input type="checkbox"/> Where possible, a minimum of corridors no longer than 22 metres in length with no blind bends |

Opportunities for social engagement are integral to ensure the person with dementia remains actively involved in their community. There are a range of activities that communities, neighbourhoods and family and friends can employ to ensure people with dementia can contribute and participate in everyday activities in a meaningful way.

| SOCIAL ENGAGEMENT | |
|---|--|
| <input type="checkbox"/> A range of community events and activities are available to meet the diverse population of people with dementia including dementia specific- activities as well as mainstream activities that are supportive of people with dementia | <input type="checkbox"/> Outreach to include people at an increased risk of social isolation including CALD, A&TSI, LGBTI, living alone and homeless to remain engaged in their community |
| <input type="checkbox"/> People with dementia are included in community initiatives and projects to provide their input and feedback | <input type="checkbox"/> People with dementia are recognised for their past and ongoing contributions to their community |
| <input type="checkbox"/> People with dementia are supported to speak at conferences and local events about dementia | <input type="checkbox"/> Dementia awareness activities and events are held to increase community knowledge and understanding of dementia |
| <input type="checkbox"/> Community events and activities are held at convenient times during the day for people with dementia | <input type="checkbox"/> Local support groups for people with dementia, their carers and family members are available e.g. Memory Cafés |
| <input type="checkbox"/> Community events and activities are held that can be attended either alone or with a carer | <input type="checkbox"/> People with dementia are regularly consulted by public, volunteer and commercial services on how best to serve them |
| <input type="checkbox"/> Affordable transportation options are available to people with dementia | <input type="checkbox"/> Hobby and interest groups provide support to assist people with dementia to remain engaged e.g. choir, walking groups |
| <input type="checkbox"/> Information about community events and activities are readily provided including details regarding accessibility of facilities and transportation options | <input type="checkbox"/> Sporting clubs and community organisations are aware of the needs of people with dementia and ensure that services are tailored to support people with dementia as needed |
| <input type="checkbox"/> Venues for community events and activities are conveniently located, accessible, well-lit and easily reached by public transport | <input type="checkbox"/> Local government, community organisations and businesses provide staff training on how to effectively communicate with customers with dementia |

Social engagement goes beyond participation in community events. For some people this could include employment, volunteering and studying. An opportunity for people with dementia to remain involved in such activities as they did pre-diagnosis is important to ensure meaningfulness and quality of life.

| EMPLOYMENT, VOLUNTEERING AND STUDY | |
|---|--|
| <input type="checkbox"/> Disability support services to engage with people with dementia | <input type="checkbox"/> Qualities of people with dementia who are employed are well promoted and recognised |
| <input type="checkbox"/> Flexible and appropriately paid opportunities for people with dementia to continue working, or become employed are promoted | <input type="checkbox"/> Training and education opportunities for people with dementia are provided and promoted |
| <input type="checkbox"/> People with dementia are consulted in order to ascertain who they can best be supported in the workplace and education and training institutions | <input type="checkbox"/> Volunteering opportunities are offered and promoted by communities, businesses and organisations to promote social engagement |
| <input type="checkbox"/> Workplaces are adapted to meet the physical needs of people with dementia | <input type="checkbox"/> Flexible options for people with dementia to volunteer are available with training, recognition, guidance and compensation for personal costs |
| <input type="checkbox"/> Decision-making bodies in public, private and voluntary sectors encourage and facilitate membership of people with dementia | <input type="checkbox"/> Training and education opportunities for people with dementia are provided and promoted |
| <input type="checkbox"/> Employment programs to support people with dementia undertake a range of activities are provided and promoted | <input type="checkbox"/> Adequate support is provided by training and education institutions to people with dementia undertaking further study |

This checklist was adapted from Innovation in Dementia, Checklists for dementia-friendly environments 2012 and the World Health Organisation Checklist of Essential Features of Age-friendly Cities 2007.

LETTER TEMPLATE TO MPS

XXXXXXX
XXXXXXX
XXXXXXX

Dear Sir/Madam,

I am writing to you in relation to the important initiative being undertaken by Alzheimer's Australia to establish the national roll out of the dementia-friendly communities initiative across Australia.

There are currently over 332,000 Australians living with dementia and over a million people involved in their care. These numbers are estimated to increase dramatically in the coming years to nearly 900,000 by 2050. At present, around 70% of people living with dementia reside in the community. The growing numbers of people living with dementia will require a shift in how we respond to the needs of people living with dementia in the community.

Dementia has considerable implications for the person diagnosed including medical, financial and social. After a diagnosis of dementia, many people report increased social isolation and stigma. Friends and even family members may stop visiting because they feel unsure of how to interact with a person who has a cognitive impairment.

The essence of dementia-friendly communities is to support people with dementia to be involved in activities and social opportunities that provide meaning and purpose in their lives for as long as possible. Through the creation of dementia-friendly communities, we will tackle social isolation and stigma through education and awareness.

The National Dementia-Friendly Communities Initiative is a low-cost approach to achieving greater community awareness, and would encourage key organisations such as banks, Centrelink, retail chains, as well as hospitals and emergency services to make their services more accessible to people with dementia. For a small investment it would have a huge impact on the quality of life of people with dementia.

I am writing in support of Alzheimer's Australia's call for a \$5 million investment in dementia-friendly communities. Without dedicated resources for this initiative it will be impossible to support communities who wish to become dementia friendly. A small investment in resources would have an incredible multiplier effect in terms of impact in reducing stigma and social isolation for people with dementia.

This issue is particularly important to me because [insert personal story]

Thank you.

Sincere regards,

DEMENTIA LANGUAGE GUIDELINES

The purpose of this paper is to promote the consistent use of appropriate, inclusive and non stigmatising language when talking about dementia and people with dementia.

What is appropriate language for talking about dementia and why do we need it?

The words used to talk about dementia can have a significant impact on how people with dementia are viewed and treated in our community.

The words used in speech and in writing can influence others' mood, self-esteem, and feelings of happiness or depression. A casual misuse of words or the use of words with negative connotations when talking about dementia in everyday conversations can have a profound impact on the person with dementia as well as on their family and friends. It can also influence how others think about dementia and increase the likelihood of a person with dementia experiencing stigma or discrimination.

Appropriate language must be:

- Accurate
- Respectful
- Inclusive
- Empowering, and
- Non stigmatising

Everyone deserves respect

Respectful language recognises that dementia is not the defining aspect in the life of someone with a diagnosis and does not reflect their capacity or level of understanding. It is important to respect others preferences about words used about them, regardless of whether the person being talked about is present or not.

Be mindful of not reinforcing stereotypes or myths about dementia

It is important to know the facts about dementia. For example, dementia is not a normal part of ageing, nor is memory loss the only symptom. Dementia can affect language, planning, problem solving, behaviour, mood and sensory perception.

Talking about dementia in a negative manner or by using incorrect terminology or inaccurate facts can reinforce stereotypes and further exacerbate the myths and misinformation about dementia.

Everyone with dementia is unique, as there are many different types of dementia and symptoms may present differently in different people.

Don't be afraid to ask

Individuals and families will express their experiences of dementia in ways that has meaning and significance to them. Not everyone will wish to have their experiences with dementia described in the same way. Where possible, ask that person directly. We can respect the dignity of each individual by respecting that person's wishes regarding use or non-use of certain terms relating to dementia.

Empowering language

It is important to use language that focuses on the abilities (not deficits) of people with dementia to help people stay positively and meaningfully engaged, and retain feelings of self-worth.

For a full copy of this guide, including background information on the preferred terms listed in the table go to: www.dementiafriendly.org.au

You can find more information about dementia at: www.fightdementia.org.au

The following are terms that people with dementia would prefer to be used when talking about dementia and people with dementia in different situations.

| CONTEXT | PREFERRED TERMS | DO NOT USE |
|--|---|---|
| TALKING ABOUT DEMENTIA | Dementia Alzheimer's disease and other forms of dementia A form of dementia A type of dementia Symptoms of dementia | Dementing illness Demented Affliction Senile dementia Senility Going on a journey |
| TALKING ABOUT PEOPLE WITH DEMENTIA | A person/people with dementia A person/people living with dementia A person/people with a diagnosis of dementia | Sufferer Victim Demented person Dementing illness Dements Afflicted Offenders, absconders or perpetrators Patient (when used outside the medical context) Subject Vacant dement He/she's fading away or disappearing Empty shell Not all there Losing him/her or someone who has lost their mind He/she's an attention seeker Inmates (referring to people with dementia in care facilities) An onion with the layers peeling away Slang expressions that are derogatory, for example, delightfully dotty, away with the fairies, got a kangaroo loose in the back paddock, a couple of cents short. 'They' (talking about all people with dementia rather than the individual) |
| A CARER, FAMILY MEMBER OR FRIEND OF A PERSON WITH DEMENTIA (About themselves) | Living alongside (someone/ a person/my partner/my mother etc) who has dementia Living with/caring for/supporting a person who has dementia Living with/caring for/supporting a person with a diagnosis of dementia Living with the impact of dementia | Person living with dementia |
| A CARER, FAMILY MEMBER OR FRIEND OF A PERSON WITH DEMENTIA (About someone else) | Family member(s) Person supporting someone living with dementia Wife/husband/partner Child/Son/Daughter Parent Friend Carer or care-giver – not everyone will like to be referred to as a carer. If possible ask what the person's preference is before using this term | |

| CONTEXT | PREFERRED TERMS | DO NOT USE |
|---|--|--|
| IMPACT OF CARING | Impact of supporting (someone/a person/my partner/my mother etc) with dementia Effect of supporting (someone/a person/my partner/my mother etc) with dementia | Carer burden Burden of caring |
| PEOPLE WITH DEMENTIA UNDER 65 | Younger onset dementia | Pre-senile dementia Early onset dementia |
| THE IMPACTS OF DEMENTIA | Disabling Challenging Life changing Stressful | Hopeless Unbearable Impossible Tragic Devastating Painful |
| SYMPTOMS OF DEMENTIA | Describe the symptom itself e.g. reduced vision, hallucinations, difficulty communicating Describe the impact it is having e.g. difficulty communicating | |
| BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA | Changed behaviour(s) Expressions of unmet need Behavioural and psychological symptoms of dementia (in a clinical context) | When talking about the symptoms Behaviour(s) of concern Challenging behaviours Difficult behaviours When talking about the person Difficult Faded away, empty shell or not all there Disappearing Aggressor Wanderer Obstructive Wetter Poor feeder Vocaliser Sexual disinhibitor Nocturnal Screamer Violent offender |
| IN RESEARCH | Dementia as a condition A person/people with dementia A person/people living with dementia A person/people with a diagnosis of dementia A participant (if in a research trial) | |
| MEDICAL | Condition | Illness Disease |

For more information:

www.fightdementia.org.au

National Dementia Helpline: 1800 100 500

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